

State of Rhode Island and Providence Plantations GUBERNATORIAL PROCLAMATION

Fabry Disease Awareness Month

WHEREAS, Fabry disease is a rare, progressive, destructive, and life-threatening inherited genetic disorder that causes children and adults to suffer a cascade of life-altering symptoms such as pain, decreased ability to perspire, intolerance to heat and exercise, unexplained fevers, chronic gastrointestinal upset, chronic fatigue, anxiety, depression, and excessive school and work absences; and

WHEREAS, Fabry disease progresses to include hearing loss, lung disease, heart disease, kidney disease, cerebrovascular disease, and other symptoms, and it often causes premature death in adults due to heart attacks, strokes and kidney failure; and

WHEREAS, Fabry disease is caused by deficient activity of the lysosomal enzyme alphagalactosidase A that causes insufficient breakdown of lipids which build up to harmful levels in the body causing lysosomal and cellular dysfunction; and

WHEREAS, there is an approved treatment for Fabry disease that must reach people who know they have Fabry disease as well as thousands of people who have not yet been recognized and diagnosed; and

WHEREAS, Fabry disease is severely under-recognized and misdiagnosed, and when diagnosed, it is often too late after irreversible organ damage occurs; and

WHEREAS, increased physician and family education are critical to increase disease recognition; and

WHEREAS, the current most commonly used estimate of classic Fabry disease incidence is about 1 in 50,000 males, and because of its x-chromosome inheritance pattern, twice as many females are potentially affected but with a random, more varied distribution of disease symptoms than in classic males, and recent studies suggest there are likely to be many times more people with Fabry disease than current rates of classic disease indicate; and

WHEREAS, an enzyme assay test for males and molecular DNA test for females can confirm Fabry disease, and can raise awareness to fight this tragic but treatable disorder; and

NOW, THEREFORE, I, Lincoln D. Chafee, Governor of the State of Rhode Island and Providence Plantations, do hereby proclaim April, 2013 as Fabry Disease Awareness Month and encourage all residents to recognize the importance of this month.

Given under my hand and the great seal of the State of Rhode Island and Providence Plantations, this _/874 day of February, 2013

Lincoln D. Chafee Governor

A. Ralph Mollis Secretary of State